

PHA EUROPE

European pulmonary hypertension association

for the patients

PHA Europe newsletter - January 2013

ERS endorsement of PH Policy brief and Call to action

The European Respiratory Society (ERS) has honoured PHA Europe with a formal endorsement of its PH Policy Brief and Call to Action, which launched in the European Parliament on June 6, 2012. Professor Laurent P. Nicod, ERS Scientific Committee chair, represented the ERS at the launch event, which was hosted by MEP Karin Kadebach with the support of MEP Hannes Swoboda, and offered public comments in support of the document.

In announcing its support, ERS leadership commented that “The ERS is pleased to join with PHA Europe and its 27 national affiliates in calling for improved access to



expert care in pulmonary hypertension, greater awareness and screening, ongoing clinical research and innovation, empowerment of PH patient groups, and increased psychosocial support for PH patients and carers. We applaud PHA Europe for taking up this call on behalf of persons living with PH across Europe, and we encourage the dissemination and uptake of the messages in the PHA

Europe Policy Brief, *Addressing the Unmet Needs of Persons Living with Pulmonary Hypertension.*”

ERS has posted information about the PH Policy Brief on its website, including a hyperlink to the PHA Europe website and a group photo featuring Prof. Nicod, Simon Gibbs, MEPS Kadenbach and Swoboda, and PHA Europe President Gerald Fischer.

<http://www.ersnet.org/eu-affairs/item/4603-ersendorsescalltoactionfor-phpatients.html>

ERS has also provided coverage of the Policy Brief in the January 17 edition of its e-newsletter, ERS Weekly, which is distributed to ERS members and friends.

Founded in 1990, the European Respiratory Society is a not-for-profit, international medical organisation dedicated to lung health and respiratory disease. It is the largest society of its kind in Europe, representing 9,000 respiratory professionals in more than 100 countries worldwide, including physicians, nurses, physiotherapists, and scientists. More than 18,000 delegates attend its Annual Congress, which is Europe’s largest annual scientific gathering in the field of respiratory medicine.

The support of a professional society of the calibre, reputation, and reach of ERS lends additional credibility to the key messages in the PH Call to Action and carries those messages out to a larger audience. The ERS endorsement represents a large step forward in PHA

Europe’s efforts – and those of its 28 national affiliates – to advocate for improved treatment and care of persons living with pulmonary hypertension.

PAH Patient and Carer Survey at World PH Symposium

Traditionally the World Symposia on PH (WSPH), which started in Geneva in 1973, have marked the progress in pulmonary hypertension science and have paved the way for further advancements. Each new edition of the WSPH has been bigger than the previous one testifying the growing interest of the stakeholders in this medical condition. Gerald Fischer, Pisana Ferrari, Mélanie Gallant Dewavrin and Yosef Gotlieb will be representing PHA Europe at the 5th edition of the WSPH, taking place in Nice (France) from February 27 to March 1, 2013, where the association will also have a booth. We are very honoured that the WSPH has accepted the abstract we submitted earlier in the year, discussing the key findings of the International Patient and Carer Survey. The abstract will feature as a poster in the scientific poster area of the symposium. The WSPH provides a wonderful opportunity to promote the results from the survey, which underline the need to recognize carers as individuals alongside the patients and provides a compelling argument for both to receive a more comprehensive standard of care. Optimum PAH management would require a multidisciplinary approach including physicians, nurses, social workers and psychologists along with patient organisations. This would allow better assessment and improvement on emotional and social wellbeing, as well as clinical symptoms. The survey highlighted that patient organisations had an important role to play in providing a range of information to patients and carers and that earlier referral by healthcare professionals to patient groups would be beneficial.

World PH Day - May 5, 2013

Lively discussions are ongoing at PH Planet, the international online platform which links together all PH associations around the world, about the organization of World PH Day on May, 2013. World PH Day has received a very wide consensus from PH associations around the world and events are expected to take place in all continents. A dedicated website is currently being set up which will allow all the participants to present their projects, share results and disseminate information about the initiative. An international committee will be in charge of coordination.

Winter 2012 edition of Mariposa Journal

The winter 2012 edition of Mariposa, PHA Europe’s official journal, was issued at the beginning of January 2013. It is available in pdf format on the PHA Europe website at www.phaeurope.org

Gerald Fischer, President
Pisana Ferrari, Vice President
PHA Europe, European Pulmonary Hypertension Association